

NICE Technology Appraisal
Vidaza/azacitidine

Patient expert statement
MDS UK Patient Support Group

Personal Statement

Paul Harford, age 66
Married, 3 sons and 4 grand-children
Retired early at 58 years old.

History of my experiences as a myelodysplastic syndrome.

Originally referred to Northwick Park Hospital in August 2005 after receiving medical treatment from my GP concerning what I can only describe as a succession of blotches appearing on my skin all over my body.

This condition started in February 2004.

I attended the dermatology clinic and was advised my condition had been diagnosed as Leucocytoclastic Vasculitis.

During my treatment blood tests revealed I was also suffering from severe anaemia.

To continue the treatment the consultant was anxious to ascertain the cause, and I was thus referred to gastro-enterology.

In February 2006 I had both an endoscope and colonoscopy examination.

Both gave me a clean bill of health - no internal bleeding was revealed which enabled the dermatology consultant to continue with my treatment for vasculitis.

During the course of 2006 I continued to attend the gastro-enterology clinic until the autumn the consultant referred me to haematology. It was at this time I was aware of a deterioration in my health becoming increasingly tired, needing rest frequently when out walking or gardening and feeling lethargic.

I support Queens Park Rangers (someone has to!!) but I found it increasingly difficult to travel by public transport the relatively short distance from Harrow to Sheperds Bush.

Just before Christmas 2006 I attended my first haematology clinic and the day after boxing day I attended the day care unit for blood transfusions.

These continued for 18 months until July 2008, every 3 weeks.

This I estimate must have involved something in the region of 60 units of blood.

At the time when I read there has been a lack of blood donors, this represents a substantial usage for one person.

Because I was retired this did not present a problem for the time I attended, normally I needed to attend for a blood test one day for the blood match and then a full day for transfusion. Whilst I incurred no costs, I am sure medical staff to provide treatment would.

I first attended King's College Hospital in the autumn of 2007 to ascertain my suitability of putting me on azacitidine. It was made clear to me that this was a drug currently on trial.

After a number of tests, the drug was first administered in April 2008 and effect of its success was soon apparent as my blood count was one of normality and I have had no blood transfusions since July 2008.

In summary azacitidine has the following considerations:

1 – no need for regular blood transfusions

2 – my blood count has stabilized and I am no longer breathless and lethargic

3 – without the drug I would see myself subject to blood transfusions indefinitely

4 – need not worry so much about my immune system (I was admitted to Northwick Park in 2008 because I did have a threatening infection on my right leg)

5 – I have read the Leukaemia Research Booklet on Myelodysplastic Syndromes which suggests continuation of blood transfusions could lead to complications.

6 – to have a prescribed drug, the costs need to be assessed against a saving in regular medical procedures that can be achieved. Patients would benefit from the time taken and costs of travel. For those in employment absence from work would be considerably reduced.

Paul Adrian Harford

16/2/2009

Further points:

I started being transfused every 4 weeks, but soon needed transfusions every 3 weeks as my blood counts were dropping faster.

It only took 3 months for the azacitidine to work.

My blood counts never fell after that (HB 16 or 17; platelets were 30 at worst point and now close to 300)

Problems putting in the canula for transfusions: I have thin veins and it sometimes took 6 attempts to put in the canula, which ended up being quite painful.

Definitely affecting Quality of Life.

Work aspect: travel to work and stairs would have become impossible. I could not have done the journey to work, as I would have been too tired and breathless.

Had I been on azacitidine, I could have worked.

Before azacitidine:

I used to have to pause 4 times to walk to the bus stop to catch my breath.

At football I knew there were 40 steps to climb.

Had to think hard whether to watch live or on TV.

I had to pause during gardening

Further point added 13 March 2009:

Method of administration might be a downside as it has to be administered as an injection and the lifespan of the drug – once prepared is only 6 hours.

If in future it can be administered by the local hospital, it would be ok, but if it has to be done in a main centre, the travel times to and from will remain to be a problem.